Thoughts on the changing meaning of disability: New eugencies or new wholeness?

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In 1927, the Supreme Court upheld the constitutionality of a Virginia law in the case that came to be known as Buck v. Bell (1927). Carrie Buck was the first person to be eugenically sterilized under the authority of that law. The law allowed a state to sterilize people diagnosed as incompetent and deemed likely to genetically transmit physical, psychological, or social disabilities to their offspring.

In writing the majority opinion in Buck v. Bell, Justice Oliver Wendell Holmes used the now-famous phrase, "Three generations of imbeciles are enough." His reasoning and his language were consistent with the eugenic view that many disabilities, including mental retardation, were largely hereditary in origin. Inherent in this view was the idea that even complex human characteristics could be traced directly to genetic sources. This belief, with the credibility afforded it by being grounded in what was accepted as "scientific fact," became a powerful force in shaping public opinion and social policy toward people with disabilities.

The eugenic evidence and the predictions in Carrie Buck's case have proven, in my own investigations and in those of others, to be grossly inaccurate. Carrie's child, Vivian, alleged to represent the "third generation of imbeciles," grew to be an honor roll student. Carrie, labeled as being the child of an "imbecile" herself, was discharged to a mountain village after being sterilized. There she married the deputy sheriff and lived a modest but productive and respectable life. Following her husband's death, she moved to a larger town where she earned her living caring for elderly and chronically ill people. Friends and employers attested to the fact that Carrie was not mentally retarded and, indeed, mental health professionals who observed her late in life found no evidence of retardation.

THE NEW EUGENICS

Carrie Buck's story is a tragic saga of one injured life. It is also an important illustration of the allure and dangers of reductionistic and deterministic thought about human beings. The ideas that created the misfortunes of Carrie Buck-that human life can be reduced to biology and that social institutions can best be guided by the realities of biological determinismhave repeatedly produced tragic results. Individuals and groups of people, including persons with disabilities, have been viewed as being inherently and unmodifiably inferior because of their biology. On that basis they have often been deprived of their dignity and rights as children and adults.

The huge strides that are currently being made in molecular biology and genetic engineering will most certainly result in scientific knowledge and medical capabilities that can change the course

of human history. These discoveries will lead to the development of technologies that will eclipse anything that medicine has known before. The potential for human benefit is enormous. The greatest challenge posed by these scientific advances, however, will be to insure that they are offered to a world of people who are seen as much more than the sum total of their biological components. To rise above the temptations and dangers of biological determinism, we must continue to see all people as deserving of the freedom and dignity of full citizenship.

In her book Politics of Women's Biology, Ruth Hubbard (1990) examined the tendency for bias against people with disabilities to be operative when "scientists and physicians are making the decisions about what lives to 'target' as not worth living" (p. 198). Hubbard found that the public may also participate in this bias when it responds with praise and unquestioning enthusiasm to measures that diminish the number of children born with disabilities. While supporting the right of a woman to terminate a pregnancy, she emphasized that a woman "must also be empowered not to terminate it, confident that the society will do what it can to enable her and the child to live fulfilling lives" (p. 197).

In Backdoor to Eugenics, Troy Duster argued that eugenics is alive and well in our society. In its present manifestation, however, it is more subtle than in the earlier eugenics movement. Eugenics is still being presented as an economic and social measure that must be considered when families make reproductive and life-sustaining decisions. It is also being presented as a matter of parental responsibility or irresponsibility. Although less overt, eugenics in its present form may be even more powerful in its impact on the lives of people with disabilities (Duster, 1990).

The danger that people with disabilities will be further devalued in a world of increasing genetic manipulation is evident in the recent remarks of James Watson. Winner of the Nobel Prize and codiscoverer of the structure of DNA, Watson spoke recently to the German Congress of Molecular Medicine. In his speech he condemned the eugenic philosophy that resulted in the atrocities of the Nazi regime. Then, in an amazing contradiction, Watson went on to advocate what might be termed "parental eugenics" concerning people with disabilities. He asserted that the "truly relevant question for most families is whether an obvious good to them will come from having a child with a major handicap. From this perspective, seeing the bright side of being handicapped is like praising the virtues of extreme poverty" (Lee, 1998, p. 16).

MARGARET MEAD AND EDUCATION FOR WHOLENESS

In Coming of Age in Samoa, Margaret Mead (1928) included a discussion of people with disabilities in the Samoan culture. She not only provided profiles of those Samoans with disabilities, but also-and perhaps more importantly-described a Samoan society that possessed "more charity towards weakness than towards misdirected strength" (p. 182).

Mead returned to this theme many years later. In 1959 she spoke to a conference sponsored by the American Association on Mental Retardation. In her remarks she referred to a group of Catholic Sisters who worked with children with mental retardation. She quoted them as saying that they were attempting to make it possible for the children that they cared for to make a "contribution in time as well as in eternity" (Mead, 1959, p. 253).

Later in her speech she returned to the example of the work of the Catholic Church and persons with mental retardation. She gave the example of a child with Down syndrome who had been tested, diagnosed, and given every opportunity for the best skill training. In her early teens, however, the child was given religious instruction, and Mead described the change that took place in the girl's life in terms of "wholeness." She said that when the girl "became Catholic, she became a human being in a way that she had not been one before . . . I think that what happened on the secular side with this little girl was that for the first time she met a situation where people were willing to teach her the whole instead of saying, `you are defective and you can only learn a part.'" (Mead, 1959, p. 260).

Mead concluded her address by elaborating on the concept of education for "wholeness." She distinguished between societies where everyone participates in all aspects of the culture (e.g., Samoa), and segmented, socially stratified societies that no longer attempt to teach the "whole" to all people (e.g., the United States). She emphasized that what make for a culture of full participants are genuine opportunities for most people to learn how to wholly participate. She warned of the "risks of complicating sections of our culture so much that we define them as things most people can't learn" (pp. 258-259).

DISABILITY AND THE ETHICAL REVOLUTION

Margaret Mead's insights add new richness to our understanding that in order for people with disabilities to be genuinely included in their own culture, that culture must strive to make accessible to them the essential "wholeness" of citizenship. That piece of a person that has been referred to as a disability must no longer be allowed to overshadow the "wholeness" of the individual.

The eugenicists looked to evolutionary theory and Mendelian genetics for moral truths. They believed that natural selection and Mendelian gene distributions could provide models for social ethics. The failure of this approach was evidenced in the needless institutionalization of those deemed to be "unfit" for social "struggle," in the sterilization of people inaccurately assessed to be the carriers of defective genes, and in the moral horrors of the Holocaust.

Moral and ethical agency is an attribute of people, not of medicine or the scientific method. The recognition that we are ethical and moral agents-and that the decisions about what we should do as opposed to what we can do rest with us-is intimidating. On the other hand, it is exciting. As the power of science for human benefit grows, so grows the importance of ethical questions about the use and the yield of that power. The great challenge of our age may be to ensure that people who make scientific and medical discoveries interact with those who seek to understand the ethical impact of those discoveries. An important facet of those exchanges must be discussion of the impact that advances in genetic science may have on the values associated with human diversity.

Simi Linton (1998) has called for conceptualizations of people, with or without disabilities, as parts of a whole and integrated universe of humanity. The key to this kind of formulation is to achieve an understanding of the complementarity and interdependence of people with differences. Commenting on the work of geneticist Barbara McClintock, Linton wrote, "If [something] doesn't fit, there's a reason, and you find what it is. Rather than overlook difference,

for instance, by naming an exception, an aberration, a contaminant, she worked to understand its place and function" (Linton, 1998, p. 120).

I hope that when the history of the early 21st century is surveyed someday, it will be evident that the genetic revolution was not solely a scientific and medical revolution. I hope that history will find it to have been an ethical revolution as well, and that the true discovery of the "wholeness" of people with disabilities was part of that revolution. I hope that it will be seen as a period when an increased awareness of the critical and uncoerced choices that only individuals and families can make about the character and direction of their lives was achieved.

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